

Phase #1 of Computer-Supported Coordinated Care Project

Peter Roessler, Sunny Consolvo, & Brett Shelton
[roessler, bshelton]@intel-research.net, sunny.consolvo@intel.com

IRS-TR-04-005

January 2004

DISCLAIMER: THIS DOCUMENT IS PROVIDED TO YOU "AS IS" WITH NO WARRANTIES WHATSOEVER, INCLUDING ANY WARRANTY OF MERCHANTABILITY, NON-INFRINGEMENT, OR FITNESS FOR ANY PARTICULAR PURPOSE. INTEL AND THE AUTHORS OF THIS DOCUMENT DISCLAIM ALL LIABILITY, INCLUDING LIABILITY FOR INFRINGEMENT OF ANY PROPRIETARY RIGHTS, RELATING TO USE OR IMPLEMENTATION OF INFORMATION IN THIS DOCUMENT. THE PROVISION OF THIS DOCUMENT TO YOU DOES NOT PROVIDE YOU WITH ANY LICENSE, EXPRESS OR IMPLIED, BY ESTOPPEL OR OTHERWISE, TO ANY INTELLECTUAL PROPERTY RIGHTS

Phase #1 of Computer-Supported Coordinated Care Project

January 2004

Peter Roessler, Sunny Consolvo, & Brett Shelton

[roessler, bshelton]@intel-research.net, sunny.consolvo@intel.com

Intel Research Seattle

1100 NE 45th Street, 6th Floor

Seattle, WA 98105

Computer-Supported Coordinated Care Project Summary

The purpose of the Computer-Supported Coordinated Care (CSCC) project is to identify the characteristics and needs of the support networks for elders who wish to remain at home (i.e., “age in place”). Ultimately our goal is to develop technology to help this population. In a three phase study towards this end, we developed an empirical approach focused on the wide range of people involved with home elder care.

We explored care networks—*support networks* of friends, families, and professionals who contribute to the care of an elder—and identified the characteristics and needs of those involved in the care—the *network members*. We examined and analyzed existing communication methods and information types and flows of the support network members. We then applied this knowledge to the design of a prototype technology, the CareNet Display, intended to support the coordination activities of network members. Further, we deployed this prototype in the homes of representative network members, gathering and analyzing data about how the technology affected their lives. As a result of this research, we recommend further exploration of the CareNet Display as well as other tools for the emerging field of Computer Supported Coordinated Care.

Our study was conducted in 3 phases:

- Phase #1: Semi-structured interviews with eldercare stakeholders to establish the CSCC approach
- Phase #2: Roundtable discussions with network members to establish design specifications for possible technologies to support the network
- Phase #3: In-situ deployment of a prototype technology, the CareNet Display, to explore how technology-based systems might improve the lives of the support network members

This report covers Phase #1. Reports for Phase #s 2 & 3 are also available.

Phase #1 Overview

As part of our investigation of eldercare in the home, we wanted to explore:

- Who provides the care the elder needs to remain at home?
- What does that group of people “look-like?”
- What types of care are being provided?
- What challenges does this group face in providing care?
- What information is important to members of that group? What is currently being shared? How comfortable are members with sharing/receiving that information?
- How and what are they communicating?
- What makes an elder’s support network an important focus for research and how might technology be used to help the group?

To answer these questions we conducted a series of semi-structured interviews in Spring 2003 with representatives of five stakeholder groups involved in eldercare: elders, familial caregivers, professional caregivers, family members, and geriatric care managers. From our findings, we propose an approach to eldercare research focused on the many people involved in the care of elders who live at home. We call this approach Computer-Supported Coordinated Care (CSCC). In this report, we include details about the interviews and discuss many of the results that contributed to this approach.

Table of Contents

Computer-Supported Coordinated Care Project Summary.....	2
Phase #1 Overview	6
Study Details.....	11
Target users.....	12
Participant profiles.....	13
Interview Sessions.....	16
Phone Diary Study.....	19
Results.....	19
Who provides the care the elder needs to remain at home?.....	21
What does that group of people “look-like?”	22
What types of care are being provided?.....	28
What challenges does this group face in providing care?.....	34
What information is important to members of that group? What is currently being shared? What is the comfort level of network members in sharing/receiving that information?	41
How and what are they communicating?.....	49
Acknowledgements.....	57
Appendix A: Pre-interview Questionnaires.....	58
Appendix B: Semi-structured Interview Guides.....	58
Appendix C: Post-interview Questionnaires.....	58
Appendix D: Phone Diary Study Interview Guide	58
Appendix E: Elder Support Network Diagrams	58

Study Details

Phase I data collection was conducted from March 13 – May 13, 2003 by Sunny Consolvo and Peter Roessler with help from Jeff Towle, Lenny Lim, and Sara Bly. It included a series of semi-structured interviews with representatives of five stakeholder groups; some participants also completed a two-week phone diary study following the interview. In this section, we discuss the target users, profiles of the participants, and details regarding the interview sessions and phone diary study.

Target users. From brief discussions with people in the community who work in eldercare, we identified five (5) stakeholder groups who are often involved in caring for elders who live at home. Those groups are:

- Elders
- Familial Caregivers
- Professional Caregivers
- Family Members
- Geriatric Care Managers

Representatives from each stakeholder group participated in the Phase I interviews.

Participant profiles. All participants were recruited by members of the research team using a variety of methods: team members gave presentations at university and local geriatric care networking conferences as well as to directors of local secular and faith-affiliated elder service organizations; posters were placed in local senior centers; and team members consulted with eldercare domain experts. Some other recruiting methods were attempted but unsuccessful: contacting senior computer resource centers; sending email to distribution lists within the University of Washington; and contacting personal friends. Participants were:

- 3 elders, all female, who receive daily care at home from familial and/or professional caregivers. All live alone in the Seattle area. Ages were from 83-93;
- 3 familial caregivers, all female, who provide regular care to elders. One is an elder's spouse and lives with him, while the others make home visits and live in their own homes. All reside in the Seattle area. Ages were from 51-80;
- 3 professional caregivers, all female, who provide regular care to elders. One has two elders living in her home in Florida; the others make home visits and live in the Seattle area. Ages were from 31-70;
- 4 family members, including one male, with elderly parents who receive daily care at home or a care facility. Participants live in the Seattle and San Francisco Bay areas. Ages were from 51-65; and
- 3 geriatric care managers, all female, who provide care through consultations and live in the Seattle area. Ages were from 46-50.

Interview Sessions. 2-3 members of the research team were present for each interview; one served as moderator and the other(s) as note-taker. Interviews were conducted in a

variety of locations based on the participant's preference: in his/her home, at Intel Research Seattle, at a local senior center, or by phone when the participant was not local to Seattle. Participants received an incentive of \$50 US. Most sessions lasted 60 – 90 minutes; the shortest was 45 minutes and the longest, 105 minutes. Data was collected in the form of participant-completed questionnaires, evaluator notes, and audio recordings.

Each session started with the participant filling out a consent form and pre-interview questionnaire [Appendix A]. This was followed by a semi-structured interview [see Appendix B for the interview guides] and concluded with the participant completing a post-interview questionnaire [Appendix C].

For non-local interviews, packets were mailed to participants in advance. The packets contained the consent form, both questionnaires, incentive payment, and instructions. Participants completed and returned the consent form and pre-interview questionnaire prior to the interview. The post-interview questionnaire and payment were in a separate sealed envelope; participants were instructed to open this after the interview was finished.

Phone Diary Study. 3 of the 4 family members also participated in a 2-week phone diary study following the interview. The study consisted of brief phone calls every weekday for 2 weeks (no calls were made on the weekends). During these calls, participants were asked about their communications with respect to the care of the elder [see Appendix D for the interview guide]. Data was collected in the form of moderator notes and audio recordings.

Results

In this section, we discuss the results of our interviews and phone diary study, grouped by the questions we were trying to answer:

- Who provides the care the elder needs to remain at home?
- What does that group of people “look-like?”
- What types of care are being provided?
- What challenges does this group face in providing care?
- What information is important to members of that group? What is currently being shared? How comfortable are members with sharing/receiving that information?
- How and what are they communicating?
- What makes an elder's support network an important focus for research?
- How could technology be used to help the group?

Who provides the care the elder needs to remain at home? In all cases, we observed that many people contribute to the care of elders who live at home. These people can be family members, friends, and often neighbors. In some cases, paid help such as professional caregivers, pharmacists, housecleaners, and doctors may also be involved on either a regular or as-needed basis. The people who contribute to the care of an elder may live in the same house as the elder, nearby, in other states, or in some cases, other

countries. We call these groups of people who contribute to the care of an elder, *support networks*, and the individuals involved, *network members*.

What does that group of people “look-like?” No two support networks we encountered were identical—for example, the number of members, relationships of members to the elder, and roles of individual members varied across networks. However, there were consistencies. Each member in the various networks fell into 1 of 3 categories regarding the impact that caregiving had on their own lives. Members either...

- make *drastic life changes*,
- make *significant contributions*, or
- have *peripheral involvement*.

Support networks usually have one member who has made drastic changes to her own life to provide the elder with the majority of the care s/he requires to remain at home. This member is often the elder’s spouse or one of the elder’s children; s/he lives near the elder, if not in the same home. In some cases, this person may be a child-in-law, sibling, or professional caregiver. Though some networks probably have more than one drastic life change member, we expect the number per support network is always small. Other network members often refer to this person as the “orchestrator,” “decision maker,” or “scheduler.” The types of life changes this person has typically made include quitting jobs, working fewer hours, finding a job with flexible hours, relocating, having the elder move in with him/her, and giving up social activities, hobbies, and travel. Caring for the elder is a primary focus of the drastic life change member’s life.

Support networks also have a few members who make *significant contributions* to the elder’s care, but have not had to make the types of changes to their lives that the drastic life change member has. These members are often the elder’s children and/or close family friends, and they live near or with the elder (i.e., we saw no instance of a significant contributor who lived at a distance). They often have a daily concern for the elder and their lives have certainly been impacted by the role of caregiving, but they are still able to maintain their own lives as a primary focus.

Other members have *peripheral involvement*. Their role is often sporadic and lightweight, usually involving occasional social support, home maintenance, and transportation. One or two peripherally involved members may be able to temporarily take a more active role, in the event that a significant contributor or drastic life changer is unavailable. These members are often the elder’s grandchildren, children who live at a distance, siblings, friends, and neighbors. The lives of these members have not been noticeably affected by the elder’s care requirements. This group usually comprises the largest portion of the elder’s support network.

Figures 1 and 2 are diagrams of two typical support networks, those of elders¹ “Grace” and “Rita.” The elder is represented in the center of each diagram. The other circles

¹ Pseudonyms have been used throughout this report to protect the identities of study participants

represent network members. Member roles are indicated by circle color and size. Large/green circles represent members who have made drastic life changes, medium/blue circles represent members who have made significant contributions, and small/pink circles represent members peripherally involved members.

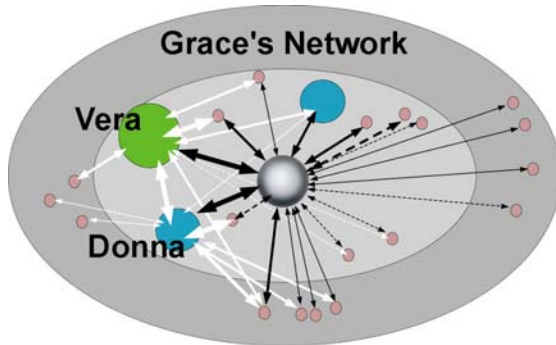


Figure 1. “Grace’s” support network

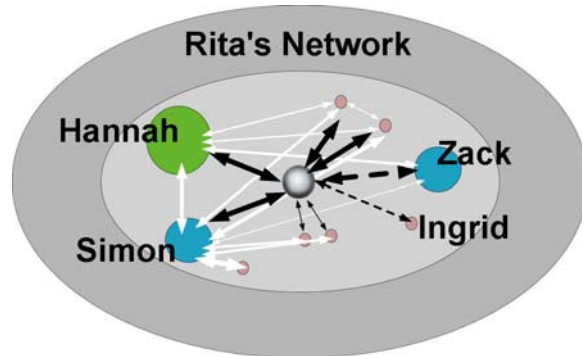


Figure 2. “Rita’s” support network

The elder is represented by the gray circle in the center. Other circles represent network members—green/large circles represent members who have made drastic life changes to care for the elder; blue/medium circles represent members who make significant contributions; and pink/small circles represent members who are peripherally involved. The distance of the circles to the elder represents physical location; the inner area contains members who live within reasonable driving distance and the outer area represents members who live at a distance. Lines show communication flow, with thickness representing volume. Solid lines represent family relations—dashed for unrelated members. The white lines highlight information flows that are about, but **do not directly involve** the elder

What types of care are being provided? Elders who live at home receive a variety of types of care based on their needs. The types of care range from help with medications and personal hygiene to various forms of home maintenance, social support, and transportation. Most networks have a member who is responsible for picking up the elder’s medications from the pharmacy and filling the elder’s Mediset® (a multi-day pill box, see Figure 3.). The drastic life changer usually also keeps track of what medications the elder takes. In many cases, a member may be assigned to remind the elder to take the medication, monitor the medication inventory, order new medication, and even administer the medication. Vera, Grace’s daughter who is a nurse specializing in geriatrics and contributes at the *drastic life change* level, prepares Grace’s medications every week. Although Grace is able to take her own blood pressure regularly, compromised motor skills make it difficult to open her pill bottles. Hygiene is another issue, particularly regarding elders with physical disabilities, dementia, or incontinence. For example, Brenda, a professional caregiver and *significant contributor* for an elder who suffered a stroke, must wash the elder’s linens and clothes, bathe her, and then help her get dressed. Trudy, a professional caregiver and *significant contributor* for Lois, bathes Lois daily and must change her adult diapers throughout the day.



Figure 3. The multi-day pill box used by an elder.

Elders may require other forms of assistance. Grace has a paid housekeeper who vacuums and cleans the bathroom and kitchen. Her grandson, a *peripherally involved* member, helps replace light bulbs and mows the lawn. Elders also often need transportation to doctor appointments, church, the grocery store, a senior center, or social events. Shared ride van services often require requests well in advance and, according to the elders who mentioned the service, are seldom punctual. In fact, several of the elders who have tried the shared ride service no longer use it. The need for assistance with financial tasks is also common. For example, Hannah, Rita's daughter who is a specialist in geriatrics and contributes at the *drastic life change* level, manages Rita's bank account to make sure she doesn't spend too much money. Trudy assists Lois by paying monthly bills, as Lois has motor skill problems which prevent her from being able to write checks. Vera helps Grace with her taxes, bills, and other legal documents.

What challenges does this group face in providing care? Several challenges were shared by the networks. For example, many members mentioned the problem of keeping everyone "on the same page." Depending on the network, this meant one of two things: either "what's right for Mom," or coordinating the elder's needs and keeping network members informed. Another issue, particularly for the *drastic life change* members, was that the rest of the network often does not understand the type of care that the elder really needs. For example, Vera mentioned that several significant contribution members do not realize how much care Grace requires. When Grace was ill recently, Vera temporarily moved in with her to ensure she did not develop respiratory problems—something for which Grace is at risk. Several network members did not think Vera needed to provide round-the-clock care, and were very vocal about it. They did not understand the seriousness of the situation and did not listen to her explanations. This resulted in additional stress for Vera and her relationships with those members.

Conditions such as dementia have raised other challenges for networks. For example, members often do not trust the elder to provide self-reports. On more than one occasion, Rita's son has called to remind her to take her medication and waited on the phone while

she claimed to ingest it, only to learn later that she did not. Rita also tells her network that she had a “proper breakfast” when she only had a cup of coffee; this is a source of concern for her network, as Rita is a Type II Diabetic who takes insulin, and her diet directly affects her condition. Unfortunately, Rita does not realize that she does not reliably communicate to her network members about significant events such as medication and breakfast. This misunderstanding has created problems in the past when members tried to get a professional caregiver to join the network.

Another challenge is that as the elder’s conditions change, so do his/her care requirements. For example, in Figure 2, the circle representing Rita is smaller than that representing Grace in Figure 1. This is because Rita can no longer provide as much care for herself as she used to, given her mild dementia. Because Rita can no longer reliably provide certain types of care for herself, other members of her network must fill in. In another example, Grace was recently diagnosed with a food allergy. This has made her diet an important and new issue for her network. Members also told us about care requirements brought on by sudden events such as a fall, stroke, or virus. For example, one morning when Rita did not meet Hannah downtown for a day of shopping, Hannah phoned a network member who lived in Rita’s building, and asked that she check on Rita. It turned out that Rita was unconscious in her apartment after falling because she did not take her morning insulin. This incident resulted in the addition of another member to Rita’s network—a 2-hour/day professional caregiver whose main responsibilities are to administer Rita’s morning insulin and ensure that she eats a proper breakfast.

Physical disabilities may also create challenges. In some instances, the elder is embarrassed enough about their physical appearance that they do not want to leave the house. For example, Kathy, a wheelchair-bound elder who resides in the home of professional caregiver Sandy, dislikes being seen in public in her wheelchair. In addition, when Kathy’s leg became swollen, she would no longer allow Sandy to bring her to church, as she didn’t want her church friends to see her condition. This has continued to alienate Kathy from others, which does not help the social aspects of her life.

What information is important to members of that group? What is currently being shared? How comfortable are members with sharing/receiving that information?

When specifically asked about the information they needed, participants often answered that they wanted general updates about how the elder is doing throughout the day. However, from answers to other questions, it was obvious that there were many types of information that affected their abilities to provide the elder with care. Not surprisingly, it was also clear that the importance of any information type to the network was dependant on the elder’s individual situation.

For example, in Grace’s network, the members who are responsible for monitoring her medication need to be notified when she takes a particular medication. It is essential that Grace takes her blood-thinning medication at the same time each day. To ensure this happens, her daughter Donna—a *significant contributor*, provides medication reminders to Grace twice per day by phone. Similarly, at least one member in Rita’s network needs to know when/if she takes her morning insulin. In many other networks, though the

members want to know what time the elder took medications and which medications were taken, a report at the end of the day would be sufficient.

The importance of the information to any network member is also closely tied to the member's role. For example, Rita's son, Zack—a *significant contributor*, keeps track of when Rita takes her medication (like Donna, he provides daily phone reminders), but seldom needs to know her transportation needs, as he works a full-time job with traditional daytime hours. In Grace's network, many of the peripherally involved members are not informed about her latest health conditions. For example, her recent food allergy was discovered due to severe and embarrassing rashes. Only Grace's daughters helped her with this (e.g., assisting with the application of prescription cream).

However, the issue of sharing information is different for each network. Mandy, a geriatric care manager and *significant contributor* for several support networks, mentions that the elder often allows open sharing of his information within the network if it means that professionals will not have to be hired. Yet, some sensitivity about sharing certain topics was identified. In fact, sometimes the network members, not the elder, may be uncomfortable about too much detail. Mandy mentioned that some members feel "squeamish" about too much detail, especially when the details consist of bad news about the elder's condition. Network members, often a drastic life changer or a significant contributor, will gauge who hears what details to spare certain network members from getting bad news. An elder's dementia has also played a role in sharing patterns. The elder will often grant Power of Attorney to a network member, forget he did so, and become upset when this member chooses how and what information to share.

We identified 20 types of information that were mentioned by the participants:

- | | | |
|--------------------|-------------------|----------------|
| ▪ activities | ▪ dressing | ▪ outings |
| ▪ bathing | ▪ falls | ▪ phone calls |
| ▪ calendar | ▪ household needs | ▪ toilet use |
| ▪ car trips | ▪ meals | ▪ visits |
| ▪ disease-specific | ▪ medications | ▪ vitals |
| measurements | ▪ messaging | ▪ water intake |
| ▪ distance walked | ▪ mood | ▪ weight |

As mentioned above, not all networks or members needed each type of information. For example, car trips were only important to networks where the elder was still driving, but in those instances, they were crucial. Toilet use was only important to networks where the elder was incontinent. Distance walked was only important to networks where the elder was still ambulatory. Falls, however, were mentioned by almost everyone, regardless of whether or not the elder had fallen before. In the cases of elders who did not have a problem with falls, it was still something the network members were concerned about. Several had researched the safety issues and "fall-proofed" the elder's homes (e.g., removing all small rugs).

How and what are they communicating? Not surprising is that the primary forms of communication are phone calls and face-to-face conversations. There was also mention of hand-written notes left at the elder's home and voice mails. At least one or two members of most support networks also use email. Though the person who is responsible for disseminating the majority of information wished the other network members would use email, it often cannot be used as a primary form of communication today because so many members will not use it². Additionally, those who do use email, often use it sporadically (maybe once/week), therefore it cannot be used to coordinate care. Other network members only use email within the context of their day job. For example, one member refuses to have a computer at home; she associates computers with work. Additionally, she is uncomfortable using her work email account for personal use.

Generally, network members communicate to “share the load” and solve problems. Hannah and two of her brothers discuss what each knows about Rita to identify new and persistent issues with Rita's dementia and diabetes. For example, Simon knows Rita's blood glucose levels and insulin intake, and Hannah observes Rita on her frequent visits. This information allows them to coordinate Rita's dietary needs so that Zack can shop for appropriate groceries.

Network members mentioned that they often forget to talk about certain things regarding the elder, especially when they need to make multiple phone calls to inform different members. Because of the difficulties involved in communicating with network members, it is usually the case that several of the network members are not informed about the elder's most up to date information. Instead, only a select few who talk with or see each other frequently know about the most recent occurrences. Because of this, several support networks have dealt with critical information about the elder's health by developing systems that keep important information in a place that is known and accessible to local network members in the event of an emergency. For example, Vera and Grace maintain a tote bag full of the information a doctor or emergency medical technician might need (see Figure 4); it is kept near the front door of Grace's house. It contains her medication information, medical history, doctor contact information, insurance, emergency contacts, and calendar. It accompanies Grace to every doctor's appointment. Hannah has a similar file for Rita.



Figure 4. Emergency information tote bag

What makes an elder's support network an important focus for research and how might technology be used to help the group? Technology can help coordinate the activities amongst network members involved in caring for elders. Currently, issues with coordinating the elder's care result in miscommunication, misunderstanding, and distrust

² One of the geriatric care managers knew of one network where email was the primary form of communication

among support networks. Other issues include unmet care needs, negative impacts on careers/personal needs, and uneven distributions of responsibility.

By targeting and supporting the coordination activities of the many network members through technology, it may be possible to involve more members at the significant contributor level, thereby reducing the excessive amount of stress normally endured by one or two members. This may also more fairly distribute the amount of free time network members have for their own personal and/or family lives. Reduced stress and life balance for network members faced with these responsibilities will only benefit the elder's overall care and quality-of-life.

Acknowledgements

We would like to thank the following people for their contributions to this research: Sara Bly, Bill Schilit, Jeff Towle, Lenny Lim, Carol Johnston, Asuman Kiyak, Linda Reeder, Karen Sisson, Jay Lundell, Brad Needham, Margie Morris, Eric Dishman, Ken Fishkin, Miriam Walker, Richard Beckwith, Scott Lederer, and Gaetano Borriello.

Appendix A:

Pre-interview Questionnaires

Includes questionnaires for:

- Elders
- Familial Caregivers
- Professional Caregivers / Geriatric Care Managers
- Concerned Family Members

Pre-Interview Questionnaire, Elder

1. Your gender: ☐ Male ☐ Female
2. How old are you?

<input type="checkbox"/> younger than 18	<input type="checkbox"/> 41-45	<input type="checkbox"/> 71-75
<input type="checkbox"/> 18-21	<input type="checkbox"/> 46-50	<input type="checkbox"/> 76-80
<input type="checkbox"/> 22-26	<input type="checkbox"/> 51-55	<input type="checkbox"/> 81-85
<input type="checkbox"/> 27-30	<input type="checkbox"/> 56-60	<input type="checkbox"/> 86-90
<input type="checkbox"/> 31-35	<input type="checkbox"/> 61-65	<input type="checkbox"/> 91 or older
<input type="checkbox"/> 36-40	<input type="checkbox"/> 66-70	
3. Where do you live? (City, State) _____
4. For how long have you lived there?

<input type="checkbox"/> 0 – 1 year	<input type="checkbox"/> 6 – 9 years
<input type="checkbox"/> 2 - 3 years	<input type="checkbox"/> 10 – 15 years
<input type="checkbox"/> 4 – 5 years	<input type="checkbox"/> 16 or more years
5. What is/was your occupation?
6. Which of the following describes your employment status? (check one)

<input type="checkbox"/> Full-time employed	<input type="checkbox"/> Retired
<input type="checkbox"/> Part-time employed	<input type="checkbox"/> Student
<input type="checkbox"/> Homemaker	<input type="checkbox"/> Unemployed
7. Which of the following describes your current marital status? (check one)

<input type="checkbox"/> Single	<input type="checkbox"/> Divorced
<input type="checkbox"/> Single, living w/someone	<input type="checkbox"/> Widowed
<input type="checkbox"/> Married	

If married, is spouse living with you? _____
8. How many children, if any, do you have? _____

Do they live nearby? ☐ no ☐ yes
9. How many siblings, if any, do you have? _____

Do they live nearby? ☐ no ☐ yes
10. Who provides care for you? (check all that apply)

<input type="checkbox"/> Professional caregiver
<input type="checkbox"/> Family member (What is their relationship to you? _____)
<input type="checkbox"/> Friend
<input type="checkbox"/> Light support from local community
<input type="checkbox"/> * Other _____
<input type="checkbox"/> I don't receive assistance
11. For how long have you received regular care?

☐

0 – 1 year

☐ 2 - 3 years

☐ 4 – 5 years

☐ 6 – 9 years

☐ 10 – 15 years

☐ 16 or more years

12. If you use the internet, where do you regularly use it? (check all that apply)

☐ Home

☐ Work / the office

☐ Public place (e.g., a library, internet café, community center)

☐ I don't use the internet

13. If you use the internet at home, what kind of connection do you have?

☐ 28.8k modem

☐ 56k modem

☐ High Speed: DSL/Cable Modem/T1/T3/etc. (circle one)

☐ Other (please include: _____)

☐ I don't know

☐ I don't use the internet

14. Which of the following technologies do you use regularly? (check all that apply)

☐ The World Wide Web: used _____ times per day/week/month (circle one)

☐ Home computer/laptop: used _____ times per day/week/month (circle one)

☐ Cell phone: used _____ times per day/week/month (circle one)

☐ PDA (Personal Digital Assistant): used _____ times per day/week/month (circle one)

☐ eMail: checked _____ times per day/week/month (circle one)

☐ Voice Mail (for home, work, or cell phone)

☐ Answering machine (for home or work phone)

☐ Text messaging: used _____ times per day/week/month (circle one)

☐ Ceiva picture frame

☐ Digital picture frame (other than the Ceiva)

☐ Other (please include: _____)



Pre-Interview Questionnaire, Familial Caregiver

1. Your gender: ☐ Male ☐ Female

2. How old are you?

<input type="checkbox"/> younger than 18	<input type="checkbox"/> 41-45	<input type="checkbox"/> 71-75
<input type="checkbox"/> 18-21	<input type="checkbox"/> 46-50	<input type="checkbox"/> 76-80
<input type="checkbox"/> 22-26	<input type="checkbox"/> 51-55	<input type="checkbox"/> 81-85
<input type="checkbox"/> 27-30	<input type="checkbox"/> 56-60	<input type="checkbox"/> 86-90
<input type="checkbox"/> 31-35	<input type="checkbox"/> 61-65	<input type="checkbox"/> 91 or older
<input type="checkbox"/> 36-40	<input type="checkbox"/> 66-70	

3. Where do you live? (City, State) _____

4. Which of the following best describes your current employment status? (check one)

<input type="checkbox"/> Full-time employed
<input type="checkbox"/> Part-time employed
<input type="checkbox"/> Student
<input type="checkbox"/> Unemployed
<input type="checkbox"/> Other (please explain: _____)

5. Which of the following best describes your role as a caregiver? (check one)

<input type="checkbox"/> I am a professional caregiver
<input type="checkbox"/> I am not a professional caregiver, but I provide regular care to a family member / friend

What is your relationship to them?

<input type="checkbox"/> spouse
<input type="checkbox"/> sibling
<input type="checkbox"/> child
<input type="checkbox"/> friend
<input type="checkbox"/> Other (please describe: _____)

6. * Have you received elder care training?

7. *If so, where?

8. * For how many elders do you currently provide care? _____

9. * For how long have you been providing care for the elder(s)?

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> 0 – 1 year | <input type="checkbox"/> 6 – 9 years |
| <input type="checkbox"/> 2 - 3 years | <input type="checkbox"/> 10 – 15 years |
| <input type="checkbox"/> 4 – 5 years | <input type="checkbox"/> 16 or more years |

10. Where do you live relative to the elder(s) for whom you care?

- ☐ in the same house
- ☐ within walking distance
- ☐ within driving distance (approximately how far? _____ miles)
- ☐ Other (please explain: _____)

11. With whom do you regularly communicate about the elder(s)? (check all that apply)

- ☐ the elder's doctor
- ☐ the elder's child(ren)
- ☐ the elder's spouse
- ☐ the elder's sibling(s)
- ☐ Other (please describe: _____)

12. What types of assistance do you regularly provide for the elder(s)?

- ☐ medication administering
- ☐ meal preparation
- ☐ household cleaning
- ☐ running errands with/for them?
 - what kind?
 - ☐ trips to the salon
 - ☐ trips to the grocery store
 - ☐ other (please describe: _____)
- ☐ Other (please describe below)



Pre-Interview Questionnaire (Professional Caregiver, Geriatric Care Manager)

1. Your gender: ☐ Male ☐ Female
2. How old are you?

<input type="checkbox"/> younger than 18	<input type="checkbox"/> 41-45	<input type="checkbox"/> 71-75
<input type="checkbox"/> 18-21	<input type="checkbox"/> 46-50	<input type="checkbox"/> 76-80
<input type="checkbox"/> 22-26	<input type="checkbox"/> 51-55	<input type="checkbox"/> 81-85
<input type="checkbox"/> 27-30	<input type="checkbox"/> 56-60	<input type="checkbox"/> 86-90
<input type="checkbox"/> 31-35	<input type="checkbox"/> 61-65	<input type="checkbox"/> 91 or older
<input type="checkbox"/> 36-40	<input type="checkbox"/> 66-70	
3. Where do you live? (City, State) _____
4. Which of the following best describes your current employment status? (check one)

<input type="checkbox"/> Full-time employed	<input type="checkbox"/> Student
<input type="checkbox"/> Part-time employed	<input type="checkbox"/> Unemployed
5. Which of the following best describes your role as a caregiver? (check one)

<input type="checkbox"/> I am a professional caregiver
<input type="checkbox"/> I am not a professional caregiver, but I provide regular care to a family member / friend

What is your relationship to them?

<input type="checkbox"/> spouse
<input type="checkbox"/> sibling
<input type="checkbox"/> child
<input type="checkbox"/> friend
<input type="checkbox"/> Other (please describe: _____)
<input type="checkbox"/> Other (please explain: _____)
6. Where did you receive your elder care training?
7. For how many elders do you currently provide care? _____
8. For how long have you been providing care for the elder(s)?

<input type="checkbox"/> 0 – 1 year	<input type="checkbox"/> 6 – 9 years
<input type="checkbox"/> 2 - 3 years	<input type="checkbox"/> 10 – 15 years
<input type="checkbox"/> 4 – 5 years	<input type="checkbox"/> 16 or more years

9. Where do you live relative to the elder(s) for whom you care?

- ☐ in the same house
- ☐ within walking distance
- ☐ within driving distance (approximately how far? _____ miles)
- ☐ Other (please explain: _____)

10. With whom do you regularly communicate about the elder(s)? (check all that apply)

- ☐ the elder's doctor
- ☐ the elder's child(ren)
- ☐ the elder's spouse
- ☐ the elder's sibling(s)
- ☐ Other (please describe: _____)

11. What types of assistance do you regularly provide for the elder(s)?

- ☐ medication administering
- ☐ meal preparation
- ☐ household cleaning
- ☐ running errands with/for them?
 - what kind?
 - ☐ trips to the salon
 - ☐ trips to the grocery store
 - ☐ other (please describe: _____)
- ☐ Other (please describe below)

12. Which of the following ways do you provide care for the elder? (check all that apply)

- ☐ in-person visits
- ☐ phone calls to/from the elder
- ☐ email to/from the elder
- ☐ Other (please describe: _____)



Pre-Interview Questionnaire, Concerned Family Member

NOTE: the term "parent" below refers to your parent **who receives regular care**.

1. Your gender: ☐ Male ☐ Female

2. How old are you?

<input type="checkbox"/> younger than 18	<input type="checkbox"/> 41-45	<input type="checkbox"/> 71-75
<input type="checkbox"/> 18-21	<input type="checkbox"/> 46-50	<input type="checkbox"/> 76-80
<input type="checkbox"/> 22-26	<input type="checkbox"/> 51-55	<input type="checkbox"/> 81-85
<input type="checkbox"/> 27-30	<input type="checkbox"/> 56-60	<input type="checkbox"/> 86-90
<input type="checkbox"/> 31-35	<input type="checkbox"/> 61-65	<input type="checkbox"/> 91 or older
<input type="checkbox"/> 36-40	<input type="checkbox"/> 66-70	

3. Where do you live? (City, State) _____

4. For how many years have you lived there?

<input type="checkbox"/> 0 – 1 year	<input type="checkbox"/> 6 – 9 years
<input type="checkbox"/> 2 - 3 years	<input type="checkbox"/> 10 – 15 years
<input type="checkbox"/> 4 – 5 years	<input type="checkbox"/> 16 or more years

5. What is your occupation?

6. Which of the following best describes your current employment status? (check one)

<input type="checkbox"/> Full-time employed	<input type="checkbox"/> Retired
<input type="checkbox"/> Part-time employed	<input type="checkbox"/> Student
<input type="checkbox"/> Homemaker	<input type="checkbox"/> Unemployed

7. Which of the following best describes your current marital status? (check one)

<input type="checkbox"/> Single	<input type="checkbox"/> Married
<input type="checkbox"/> Single, living w/someone	<input type="checkbox"/> Divorced
	<input type="checkbox"/> Widowed

8. How many children, if any, do you have? _____



9. For how long have you been concerned about your parent's daily well-being?

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> 0 – 1 year | <input type="checkbox"/> 6 – 9 years |
| <input type="checkbox"/> 2 – 3 years | <input type="checkbox"/> 10 – 15 years |
| <input type="checkbox"/> 4 – 5 years | <input type="checkbox"/> 16 or more years |

10. Which of the following best describes the situation with your parent? (check one)

- ☐ I am the only close family/friend who has a regular concern about my parent's care
- ☐ I share the concern for my parent with one or more close family members/friends, but I have primary responsibility for my parent
- ☐ I share the concern for my parent with one or more close family members/friends, but I **do not** have primary responsibility for my parent
- ☐ I share the concern for my parent equally with one or more close family members/friends

11. Which of the following technologies do you use regularly? (check all that apply)

- ☐ The World Wide Web
 - ♦ used _____ times per day/week/month (circle one)
- ☐ Home computer or laptop
 - ♦ used _____ times per day/week/month (circle one)
- ☐ Cell phone
 - ♦ used _____ times per day/week/month (circle one)
- ☐ PDA (personal Digital Assistant)
 - ♦ used _____ times per day/week/month (circle one)
- ☐ eMail
 - ♦ checked _____ times per day/week/month (circle one)
- ☐ Voice Mail (for home, work, or cell phone)
- ☐ Answering machine (for home or work phone)
- ☐ Text messaging
 - ♦ used _____ times per day/week/month (circle one)
- ☐ Ceiva picture frame
 - ♦ do you own the frame? ☐ no ☐ yes
 - ♦ do you update someone else's frame? ☐ no ☐ yes
- ☐ Digital picture frame (other than the Ceiva)
 - ♦ do you own the frame? ☐ no ☐ yes
 - ♦ do you update someone else's frame? ☐ no ☐ yes
- ☐ Other (please include: _____)



12. Where do you regularly use the internet (work & personal use)? (check all that apply)

- ☐ Home
- ☐ Work / the office
- ☐ Public place (e.g., a library, internet café)

13. If you use the internet at home, what kind of connection do you have?

- ☐ 28.8k modem
- ☐ 56k modem
- ☐ High Speed: DSL/Cable Modem/T1/T3/etc. (circle one)
- ☐ Other (please include: _____)
- ☐ I don't know



Appendix B:

Interview Guides

Includes interview guides for:

- Elders
- Familial Caregivers
- Professional Caregivers / Geriatric Care Managers
- Concerned Family Members

Individual Interviews with Elders

Background/Warm-up for Elders

1. *Introductions, explain basic purpose of study (very simple overview).*
2. How long have you lived in this area? What did you do here (if lived here a long time) OR where did you live before you moved here? If fairly recently here, ask why they moved here.
3. Do you live alone? If not, who else lives here?
4. *Probe for the family members and where they live in relation to one another, particularly the children {there could be siblings or nieces/nephews, etc}.*
 - a. Do you have family members who live in the area? Who?
 - b. How close or far do they each live {note children, siblings, close nieces and nephews, extended family members}?
 - c. How long have they lived in this area?
 - d. Why did they choose to move here?

[Might be good to draw a sketch here of the family members and their relative geographic distances from one another. You could use this as a basis for several interview questions, annotating it as you talk.]
5. How long have you been living with assisted care?
 - a. Who provides you with care?
 - b. Have you ever received care from anyone else?
 - c. What kind of care do you receive?
 - d. How often?
6. What are your medical conditions?

Main Questions

1. Are you in contact with your children (or immediate family)? *[You might want to do this for several of their children, not just the adult child you've targeted.]*
2. If so, how do you communicate {phone, visits, letters, email, etc.} (Additions per Sara's suggestion. Not sure if this is an appropriate place, but seems that this might come through anyway and we can come back to it later if response is interesting)
 - a. Which of these are most accessible to you? Are you able to see well enough to dial numbers on the phone? Do you have trouble writing/typing?
 - b. Does this affect the communication/ how you communicate?
3. How often {for each method mentioned}?
4. What things do you usually discuss or share? *[Again, you can follow naturally from whatever methods are being mentioned.]*
5. Could you give me an example of the last time you were in touch with one another?
 - a. When was that?
 - b. How did you get in touch? Who initiated it?
 - c. What did you discuss or share? *[i.e. try to get specific instances as often as possible – maybe even start with a specific example, usually the last one they*

remember, rather than more general questions.] Probably want a couple more examples, especially if they use several means of contacting each other.

6. Are these communications important to you? Why? Is anything missing?
 - a. Does your child want any particular information on a regular basis?
 - b. Does your child want regular information about your care?
7. What do you tell your child? *[Yes, this may be redundant with what you've already discussed in which case you can skip over these lightly – but note they may get a lot of information from another sibling or someone other than the parent discussed in #1]*
8. Is there information you would rather not share with your child?
9. Is there information you would like your child to have that s/he doesn't get?
10. Is there any information shared that you wish were not? What kinds of information? Why is it shared?
11. Is your child in contact with your caregiver?
 - d. who initiates the contact?
 - e. how do they communicate? (e.g., phone, in person, email) Are you there?
 - f. how do you feel about their contact? Do you know what they talk about? How does that feel for you?
 - g. Can you tell me about the last time your child had contact with your caregiver?
12. How do you feel about your assisted care arrangements?
 - h. What are some of the good things about this arrangement?
 - i. What are some of the drawbacks?



Interviews with Familial Caregivers

Background/Warm-up for Familial Caregivers

1. *Introductions, explain basic purpose of study (very simple overview).*
2. *training/experience questions from Pre-questionnaire #s 6, 7, & 9.*
3. How long have you lived in this area? What did you do here (if lived here a long time) OR where did you live before you moved here? If fairly recently here, ask why they moved here.
4. Do you work or have regular activities outside your home?
5. *Probe for the family members and where they live in relation to one another, particularly the children {note there may be siblings or nieces/nephews, etc}.*

Do you have family members who live in the area? Who? How close or far do they each live {note children, siblings, close nieces and nephews, extended family members}? How long have they lived in this area? Why did they choose to move here?
6. Number of elders currently caring for from *Pre-questionnaire #8.*
7. How long have you been providing care for a family member(s)?
 - a. What kind of care do you provide? [*Pre-questionnaire #12*]
 - b. How often?
8. Does anyone else help with care? Who? What do they do?
9. What sorts of innovations help you provide care?

Main Questions

1. What type of information do you track or document about elders in your care?
 - a. Why do you track this information?
 - b. How do you track this information?
 - c. How do you record it? [*hand-written on paper? input into electronic format? fill out forms?*]
 - d. When do you record the information and where are you when you record it? [*as it happens, later that day ?, at the end of the day—week?*]
 - e. Where is the information kept?
 - f. How is the information used?
 - g. [*if not answered*] Who uses the information?
2. Do you have contact with any other family members?
 - a. How many? Who initiates the contact?
 - b. How do you communicate with them? [*phone, in person, email*]
 - c. How frequently do you communicate with them?
 - d. What do you talk about? Is there specific information the family member(s) want(s)?
 - e. How does your elder feel about that contact?
 - 1) Do they know what you talk about?
 - f. Tell me about the last time you had contact with an adult child of one of the elders in your care...

- g. Are there any types of information that you're uncomfortable sharing with the elder's children?
 - 1) What types of information?
 - 2) Why is it uncomfortable for you?
 - 3) Is it shared? Why?
- h. Is there information that isn't shared that you think would be helpful to the adult child?
 - 1) Why isn't this information currently being shared?
- i. What are some of the challenges you face in providing information to adult children?
- 3. What types of social interactions do the elders for whom you provide care normally have? Friends, family?
 - a. How often do these interactions take place?
 - b. Describe the type of interactions you observe.
- 4. *[Refer to earlier mentions of documented information, information the adult child wants, helpful information not shared, information uncomfortably shared.]*
 - a. If it were possible to automatically track/record anything about the elder, what would be most useful to you?
 - b. If it were possible to automatically share information with people concerned about the elder...
 - i. What information would be shared?
 - ii. whom would the information be shared?
 - iii. Imagine the information could be shared automatically, but had to be collected manually by you (i.e., it couldn't be automatically recorded). Does this change the information that should be shared?
 - 1. Would this mean you have to track and document more than you are already doing? *[question #8 above]*



Interviews with Professional Caregivers and Geriatric Care Managers

Background/Warm-up for Professional Caregivers

1. *Introductions, explain basic purpose of study.*
2. *training/experience questions from Pre-questionnaire #s 6 & 8*
3. Tell me about your job? What do you enjoy? What's difficult? How long have you been doing this work?
4. *Number of elders currently caring for from Pre-questionnaire #7*
 - a. How much time do you spend w/ each?
5. What does a typical week look like for you? *[schedule, hours]*
6. What type of care do you provide? *[Pre-questionnaire #11]*
7. Does anyone other than you care for the elders?
 - a. Who?
 - b. What do they do?

Main Questions

8. What type of information do you track or document about elders in your care?
 - a. Why do you track this information?
 - b. How do you track this information?
 - c. How do you record it? *[hand-written on paper? input into electronic format? fill out forms?]*
 - d. When do you record the information and where are you when you record it? *[as it happens, later that day, ?, at the end of the week—onsite? at your home/office? wherever it's convenient?]*
 - e. Where is the information kept?
 - f. How is the information used?
 - g. *[if not answered]* Who uses the information?
9. Do you have contact with any of the adult children?
 - a. How many? Who initiates the contact?
 - b. How do you communicate with them? *[phone, in person, email]*
 - c. How frequently do you communicate with them?
 - d. What do you talk about? Is there specific information the adult child(ren) want(s)?

- e. How does the elder feel about that contact?
 - i. Do they know what you talk about?
- f. Tell me about the last time you had contact with an adult child of one of the elders in your care...
- g. Are there any types of information that you're uncomfortable sharing with the elder's children?
 - i. What types of information?
 - ii. Why is it uncomfortable for you?
 - iii. Is it shared? Why?
- h. Is there information that isn't shared that you think would be helpful to the adult child?
 - i. Why isn't this information currently being shared?
- i. What are some of the challenges you face in providing information to adult children?
- 10. What types of social interactions do the elders for whom you provide care usually have? *[Friends, family]*
 - a) How often these interactions take place?
 - b) Describe the type of interactions you observe.
- 11. *[Refer to earlier mentions of documented information, information the adult child wants, helpful information not shared, information uncomfortably shared.]*
 - a) If it were possible to automatically track/record anything about the elder, what would be most useful to you?
 - b) If it were possible to automatically share information with people concerned about the elder...
 - ii. What information would be shared?
 - iii. With whom would the information be shared?
 - iv. Imagine the information could be shared automatically, but had to be collected manually by you (i.e., it couldn't be automatically recorded). Does this change the information that should be shared?
 - i. Would this mean you have to track and document more than you are already doing? *[question #8 above]*



Individual Interviews with Concerned Family Members

Background/Warm-up for Concerned Family Members

1. *Introductions, explain basic purpose of study (very simple overview).*
2. How long have you lived in this area? What do you do here?
3. *Probe for the family members and where they live in relation to one another, particularly the siblings and other parent of the Adult Child and Elder pair.*
 - a. Do you have family members who live in the area? Who?
 - b. How close or far do they each live {note siblings, children living away from home, parents, extended family members}?
 - c. How long have they lived in this area?
 - d. Why did they choose to move here?

[Might be good to draw a sketch here of the family members and their relative geographic distances from one another. You could use this as a basis for several interview questions, annotating it as you talk.]
4. Do your parent(s) require any care? (Yes, you know this from the recruitment but it never hurts to hear it again – and you might find there are other parents, e.g. in-laws, who also require care.)

Probe for the nature of the care, including

- a. How long has your parent been receiving care?
- b. What kind of care does your parent need?
- c. Who provides your parent with care?
- d. Do you share any responsibilities with the care provider?

Main Questions

2. Are you in contact with your parent (be specific that you're now discussing the parent who requires care)?
 - a. If so, how do you communicate {phone, visits, letters, email, etc.} How often {for each method mentioned}?
 - b. What things do you usually discuss or share? [Again, you can follow naturally from whatever methods are being mentioned.]
 - c. Could you give me an example of the last time you were in touch with one another?
 - i. When was that?
 - ii. How did you get in touch? Who initiated it?
 - iii. What did you discuss or share? [i.e. try to get specific instances as often as possible – maybe even start with a specific example, usually the last one they remember, rather than more general questions.] *Probably want a couple more examples, especially if they use several means of contacting each other.*
 - d. Are these communications important to you? Why? Is there anything missing?
3. In general, what information about your parent do you want to know on a regular basis?
 - a. how do you get it? [Yes, this may be redundant with what you've already discussed in which case you can skip over these lightly – but note they may

get a lot of information from another sibling or someone other than the parent discussed in #1]

- b. what do you do with the information?
 - c. do you communicate it to anyone else? Who?
 - d. Is there information you don't get that you would like to have? If so, what information?
 - e. Can you give me an example of the last time you can remember that you wanted information you didn't have? What did you do?
4. How often are you in contact with your parent's caregiver?
- a. who initiates the contact?
 - b. how do you communicate with them? (e.g., phone, in person, email)
 - c. what do you talk about?
 - d. is there anything you'd like to talk with them about, but for some reason don't?
 - i. what? why?



Appendix C:

Post-interview Questionnaires

Includes questionnaires for:

- Elders
- Familial Caregivers / Concerned Family Members
- Geriatric Care Managers
- Professional Caregivers

Post-Interview Questionnaire, Elder

Instructions: Please circle the item on the scale that best approximates your level of agreement with each statement.

I am comfortable...

... if any information about me is shared with any of my family members who ask	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... if certain information about me is shared with any of my family members who ask	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... if any information about me is shared with certain family members who ask	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... if certain information about me is shared with certain family members who ask	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... if any information about me is shared with my family members at the discretion of my caregiver	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... if information about me is shared with my family members at my discretion	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>

Instructions: Please indicate who you feel comfortable sharing each type of information with by **checking all of the people who apply**.

1. It is okay to share that there was a **problem with my medication** with...
 - ☐ my medical doctor
 - ☐ my caregiver
 - ☐ certain neighbors
 - ☐ certain friends
 - ☐ my geriatric care manager / social worker / case worker
 - ☐ certain family members who live nearby
 - ☐ certain family members who live far away
 - ☐ it is **not okay to share** that there was a **problem with my medication** with anyone

2. It is okay to share that **I didn't take my medication** with...
 - ☐ my medical doctor
 - ☐ my caregiver
 - ☐ certain neighbors
 - ☐ certain friends
 - ☐ my geriatric care manager / social worker / case worker
 - ☐ certain family members who live nearby
 - ☐ certain family members who live far away
 - ☐ it is **not okay to share** that **I didn't take my medication** with anyone

3. It is okay to share the **details about the medication I took** (for example, what I took, the dosages, and when I took them) with...
 - ☐ my medical doctor
 - ☐ my caregiver
 - ☐ certain neighbors
 - ☐ certain friends
 - ☐ my geriatric care manager / social worker / case worker
 - ☐ certain family members who live nearby
 - ☐ certain family members who live far away
 - ☐ it is **not okay to share** the **details about the medication I took** with anyone

4. It is okay to share that **I took my medication** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share** that **I took my medication** with anyone

5. It is okay to share **who visited me** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share who visited me** with anyone

6. It is okay to share that **certain people visited me** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share** that **certain people visited me** with anyone

7. It is okay to share that **I had a visitor (no additional details)** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share** that **I had a visitor** with anyone

8. It is okay to share that **I went out of the house and where I went** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share** that **I went out of the house and where I went** with anyone

9. It is okay to share that **I went out of the house & how long I was gone** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share** that **I went out of the house and how long I was gone** with anyone

10. It is okay to share that **I went out of the house (no additional details)** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share** that **I went out of the house** with anyone

11. It is okay to share that **I didn't eat a meal (breakfast, lunch, or dinner)** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share** that **I didn't eat a meal** with anyone

12. It is okay to share **what I ate (breakfast, lunch, and dinner)** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share what I ate** with anyone

13. It is okay to share that **I ate a meal (breakfast, lunch, or dinner)** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share** that **I ate a meal** with anyone

14. It is okay to share **how far I've walked each day** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share how many steps I've taken** with anyone

15. It is okay to share **measurements related to a specific disease of mine (for example, my blood pressure or blood glucose level)** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share measurements related to a specific disease** with anyone

16. It is okay to share that **I had a fall** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ it is **not okay to share** that **I had a fall** with anyone

17. It is okay to share that **I took the car out for a drive** with...

- ☐ my medical doctor
- ☐ my caregiver
- ☐ certain neighbors
- ☐ certain friends
- ☐ my geriatric care manager / social worker / case worker
- ☐ certain family members who live nearby
- ☐ certain family members who live far away
- ☐ I don't drive
- ☐ it is **not okay to share** that **I took the car out for a drive** with anyone

18. Is there any other information about you (that's not mentioned above) that you would want to be shared with someone?

- ☐ No ☐ Yes

If yes, **what** would you want to be shared? **With whom** would you want it to be shared?

Thank you for your help!



Post-Interview Questionnaire; Concerned Family Member, Familial Caregiver

Instructions: Please circle the item on the scale that best approximates your level of agreement with each statement.

It is important that I be notified...

...if something goes wrong with my parent's medication.	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... immediately if something goes wrong with my parent's medication.	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...if my parent misses a medication.	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... immediately if my parent misses a medication.	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...that my parent took their medication.	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...of details about my parent's medication (i.e., what was taken, dose, and time taken).	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...when my parent is visited by somebody	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...of who visited my parent	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...of who visited my parent and what they did during the visit	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...when my parent goes out	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...of my parent's daily activity level	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...of the activities my parent does each day	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...if my parent skips a meal	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...if my parent ate breakfast, lunch, and dinner each day	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...when my parent eats a meal	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...of what my parent ate at their meal	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
...of how much my parent is drinking daily	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>

If you could receive any information about your parent, what would your top 5 choices be?

- _____
how frequently?
☐ immediately ☐ daily ☐ weekly ☐ other _____
- _____
how frequently?
☐ immediately ☐ daily ☐ weekly ☐ other _____
- _____
how frequently?
☐ immediately ☐ daily ☐ weekly ☐ other _____
- _____
how frequently?
☐ immediately ☐ daily ☐ weekly ☐ other _____
- _____
how frequently?
☐ immediately ☐ daily ☐ weekly ☐ other _____

Instructions: Please consider the following ways you might receive information about your parent and rank them accordingly.

phone call from caregiver / assisted living facility	<i>don't understand</i>	<i>definitely not</i>	<i>probably not</i>	<i>not sure</i>	<i>probably</i>	<i>definitely</i>
phone call from parent	<i>don't understand</i>	<i>definitely not</i>	<i>probably not</i>	<i>not sure</i>	<i>probably</i>	<i>definitely</i>
phone number you could call to listen to a recording of the most recent information	<i>don't understand</i>	<i>definitely not</i>	<i>probably not</i>	<i>not sure</i>	<i>probably</i>	<i>definitely</i>
daily email	<i>don't understand</i>	<i>definitely not</i>	<i>probably not</i>	<i>not sure</i>	<i>probably</i>	<i>definitely</i>
website that would show the most recent information (account required to access)	<i>don't understand</i>	<i>definitely not</i>	<i>probably not</i>	<i>not sure</i>	<i>probably</i>	<i>definitely</i>
a display you could keep in your house/at work that would show the most recent information	<i>don't understand</i>	<i>definitely not</i>	<i>probably not</i>	<i>not sure</i>	<i>probably</i>	<i>definitely</i>
a display you could carry that would show the most recent information	<i>don't understand</i>	<i>definitely not</i>	<i>probably not</i>	<i>not sure</i>	<i>probably</i>	<i>definitely</i>
a special background for your computer's desktop that would show the most recent information	<i>don't understand</i>	<i>definitely not</i>	<i>probably not</i>	<i>not sure</i>	<i>probably</i>	<i>definitely</i>

Thank you for your help!



Post-Interview Questionnaire, Geriatric Care Manager

Instructions: Please circle the item on the scale that best approximates your level of agreement with each statement.

I am comfortable...

... sharing any information about the elder for whom I care with any of his/her family members who ask	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... sharing any information about the elder for whom I care with select members of his/her family who ask	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... sharing information about the elder for whom I care with members of his/her family at my discretion	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... sharing information about the elder for whom I care with members of his/her family at the discretion of the elder	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>

If anything about the elder for whom you care could be recorded or tracked automatically, what would your top 5 choices be?

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

If anything about the elder for whom you care could be communicated automatically to select family members, what would your top 5 choices be?

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Thank you for your help!



Post-Interview Questionnaire, Professional Caregiver

Instructions: Please circle the item on the scale that best approximates your level of agreement with each statement.

I am comfortable...

... sharing any information about the elder for whom I care with any of his/her family members who ask	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... sharing any information about the elder for whom I care with select members of his/her family who ask	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... sharing information about the elder for whom I care with members of his/her family at my discretion	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>
... sharing information about the elder for whom I care with members of his/her family at the discretion of the elder	<i>strongly disagree</i>	<i>disagree</i>	<i>not sure</i>	<i>agree</i>	<i>strongly agree</i>

If anything about the elder for whom you care could be recorded or tracked automatically, what would your top 5 choices be?

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

If anything about the elder for whom you care could be communicated automatically to select family members, what would your top 5 choices be?

- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____
- ☐ _____

Instructions: Please indicate who you feel comfortable sharing each type of information with by **checking all who apply**.

1. What information do you want or need about the elder for whom you provide care? Please **check all that apply**.

- ☐ That s/he didn't take their medication
- ☐ details about the medication s/he took (for example, what s/he took, the dosages, and when s/he took them)
- ☐ that s/he took their medication
- ☐ who visited him/her
- ☐ that certain people visited him/her
- ☐ that s/he had a visitor (no additional details)
- ☐ that s/he went out of the house and where s/he went
- ☐ that s/he went out of the house & how long s/he were gone
- ☐ that s/he went out of the house (no additional details)
- ☐ that s/he didn't eat a meal (breakfast, lunch, or dinner)
- ☐ what s/he ate (breakfast, lunch, and dinner)
- ☐ that s/he ate a meal (breakfast, lunch, or dinner)
- ☐ how many steps s/he has taken each day
- ☐ measurements related to a specific disease of his/hers (for example, his/her blood pressure or blood glucose level)
- ☐ that s/he had a fall

2. Does the elder drive?

- ☐ No ☐ Yes

If yes, do you want or need to know when s/he has taken the car out for a drive?

- ☐ No ☐ Yes

Thank you for your help!



Appendix D:

Phone Diary Study Interview Guide

The goal of the phone diary study was to document the trends in the concerned family members' daily communications with the elder and his primary caregiver. The phone calls helped augment the interview data.

Scripted Questions:

- How is your day going?
- What do you have going on today?
- Were you in touch with your parent or the caregiver?
- Who? How?
- What did you talk about?
- What happened? Anything out of the ordinary? Issues?
- How was your parent today? Caregiver?
- Good/bad interaction? Opinions/feelings?
- Are you stressed out about anything today? What's the cause? Parent-related?

Appendix E:

Elder Support Network Diagrams

Support network diagrams for elders Grace, Rita, Kathy, Lois, and Judy. The elder is in the center of each diagram. Circles represent network members; circle size represents how much support the network member provides. The distance of the circles to the elder represents physical location; the inner area contains members who live within reasonable driving distance and the outer area represents members who live at a distance. Lines show communication flow with respect to communication method indicated on each diagram, with thickness representing volume. Solid lines represent family relations—dashed for unrelated members. White lines show information flows that are about, but do not directly involve the elder. Diagrams are as complete as possible based on the information from our interviews. Diagrams for elders Grace and Rita should be the most complete, as we spoke to several members of each of those support networks.

